

DAERI – A Case Database for Adverse Events related to the Internet

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While we have a good understanding of the potential benefits of the Web for consumers in terms of patient empowerment and education (and we know what outcomes we should look at), we do not know much about potential mechanisms of harm through Internet applications. Collection of critical incidents is needed to ensure that we learn from our mistakes. Since 2001 we systematically collect published and unpublished cases in the "Database of Adverse Events Related to the Internet" (<http://www.medcertain.org/daeri>). We solicit and collect cases submitted by practitioners and patients, but also include cases reported in lay publications such as newspapers. The cases stored in the database will be published as an aggregate, annual report. Cases include e.g. misdiagnosis or wrong treatments due to online prescription of drugs or medical consulting via the Internet, discontinuation of life-saving treatments due to misinterpretation of Internet information by patients, the addictive potential of the Internet, the potential of the Internet to encourage suicide. As an incentive to submit cases we pay a small honorarium to the submitting physician.

Much has been written, commented and speculated about the variable information quality of information found on the Internet and the presumed impact of the Internet on patients. Other issues discussed in the medical community include the assumed harmful effects of Internet prescribing of prescription drugs or medical consulting in the absence of a pre-existing face-to-face patient-physician relationship, the negative impact of pornographic (and other "adult") material on minors, the addictive potential of the Internet, or the potential of the Internet to promote suicide. However, very little evidence is available on how well founded these concerns are. The "Database of Adverse Events Related to the Internet (DAERI)" is a first attempt to systematically collect the "evidence" in form of case studies on possible harm caused by the Internet.[1]

By putting up this database we are not implying that the Internet is harmful to patients or the patient-physician relationship - on the contrary, the positive effects on consumer health are probably outweighing the potential negative effects [2]. However, similar to pharmacovigilance and surveillance systems for monitoring adverse drug effects, reporting and systematic collection of critical incidents is needed for continuous quality control and for improving health communication. In the near absence

of pertinent information published in the peer-reviewed literature [3], we aim to gather qualitative data needed to suggest design features or interventions to minimize potential risks and pitfalls involved in consumer health informatics. Such qualitative data are also needed to suggest future process and outcome measures for systematic and experimental studies investigating possible problems related to the Internet and to quantify (investigate the prevalence of) possible problems.

Employing a broad definition of "harm", we invite health professionals to submit short descriptions of events where

- patients have been harmed (psychologically or physically) by misinformation on the Internet
- patients have misinterpreted information on the Internet
- patients who have delayed consultation with health professionals because of Internet research or a Internet diagnosis
- patients who misdiagnosed themselves
- patients who have received a wrong diagnosis or harmful advice from a "cyberdoctor"
- patients who consulted their physicians recurrently or needlessly due to Internet-searches ("Cyberhypocondria")
- patients who ordered drugs or products online which have been harmful for their health
- patients who attempted or committed suicide due to the visit of websites or newsgroups containing suicide instructions etc.

To submit a case, a brief online-questionnaire has to be filled in. Submitters will receive a small honorarium as incentive.

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References

1. Eysenbach G, Köhler C. Does the internet harm health? Database of adverse events related to the internet has been set up. *BMJ* 2002;324:239
2. Bessell TL, McDonald S, Silagy CA, Anderson JN, Hiller JE, Sansom LN. Do Internet interventions for consumers cause more harm than good? A systematic review. *Health Expect* 5 (1):28-37, 2002.
3. Crocco AG, Villasis-Keever M, Jadad AR. Analysis of cases of harm associated with use of health information on the internet. *JAMA* 287 (21):2869-2871, 2002